

Individualized care plans for transplant recipients: an example of patient-centered research

What did researchers want to share?

Researchers wanted to point out the importance of patient-centered research and share an example of such research. Patient-centered research involves patients in every step of the research process: deciding which research questions to ask, doing the research study, and sharing the results. The goal of patient-centered research is to do research that helps patients make important health decisions.

What did they do?

Researchers from Be The Match and the CIBMTR are studying individualized care plans for blood and marrow transplant recipients. The care plans will be specific to each patient, based on the treatments they received. And the plans will recommend care for several years after transplant. Researchers think the care plans will help transplant recipients be:

- More confident about preventive care
- More likely to follow health recommendations
- Healthier
- Less stressed

There are 2 parts to this research study. The 1st part is complete. Researchers talked to patients and caregivers, non-transplant doctors, and transplant doctors about what should be in the care plan and how it should look. Then the researchers used this advice to make a care plan template.

In the 2nd part of the study, researchers will compare 250 adult transplant recipients who get the care plan with 250 recipients who don't. Researchers will randomly decide who gets an individualized care plan. Recipients who don't get a care plan will get normal care after transplant. Then researchers will see whether recipients who get a care plan are healthier and less stressed than recipients who do not get a care plan.

Researchers involve patients in every step of the individualized care plan research process. This helps researchers make sure the results will be helpful for transplant recipients and their loved ones.

Important Points:

- **Patients are involved in every step of the research process.**
- **Researchers think the care plans will help patients be healthier and less stressed after transplant.**

Why is this important?

The individualized care plan study is an example of patient-centered research. It shows that researchers can involve patients in every step of the research process. And it shows the research study is better when patients are involved.

What else should I keep in mind about this article?

The individualized care plan study is not done yet. Only some of the recipients in the study will get an individualized care plan. All other recipients will have to wait until the study is over to get one.

Questions to ask your doctor

If you had a transplant in the last 1-5 years, you may want to ask:

- Are you part of the individualized care plan study? May I be part of it?
- What symptoms should I watch out for?
- What type of check-ups and tests do you recommend for me?

Learn more about

- [This research study](#)
- [Life after transplant](#)
- [After transplant care toolkit](#)

Source:

Clauser SB, Gayer C, Murphy E et al. Patient centeredness and engagement in quality-of-care oncology research. *Journal of Oncology Practice*. 2015 May 1; 11(3):176-179. Epub 2015 Apr 7.

About this research summary

Ground-breaking research into blood and marrow transplant is happening every day. That research is having a significant impact on the survival and quality of life of thousands of transplant patients. But the research is written by scientists for scientists. By providing research news in an easy-to-understand way, patients, caregivers, and families have access to useful information that can help them make treatment decisions.

This information is provided on behalf of the Consumer Advocacy Committee of the CIBMTR[®] (Center for International Blood and Marrow Transplant Research[®]). The CIBMTR is a research collaboration between the National Marrow Donor Program[®]/Be The Match[®] and the Medical College of Wisconsin.

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